The Caregiver

Newsletter of the Duke Family Support Program

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Inside This Issue

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Duke Family Support Program

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NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

Eastern NC Alzheimer's Association – November 7 & 8, 2002 – Annual Education Conference, Sheraton Chapel Hill. For more information call (919) 832-3732. Community & Family Caregiver Training & Facility Training schedules are available from Vicki Wood at (336) 376-9860. Early Onset Support Group: Monthly new group for individuals with early stage Alzheimer's disease in Raleigh. Call 919-832-3732.

Western Carolina Chapter Alzheimer's Association – The Western Carolina Chapter of the Alzheimer's Association now has four offices to better serve our area. Memory Walks are every weekend this fall through November 3. Call for information. November 6, 2002: Annual Fall Caregiver Conference. YMCA Blue Ridge Assembly in Black Mountain, NC. Keynote Speakers: Dr. Eric Tangalos of the Mayo Clinic, Rochester, Minnesota and Lisa Gwyther from Duke. For family caregivers and health professionals. 5.25 CEUs. March 25, 2003: Annual Spring Conference: Featured Speaker: Kathryn Perez Riley, Ph.D.—Nun Study.

Risk Factors for Alzheimer's Affect Decline and Symptom Onset

An Interview with Kathleen Welsh-Bohmer, PhD
Associate Director, Bryan ADRC
Principal Investigator
Cache County Memory and Aging Study

New findings from the Cache County Memory and Aging Study add further evidence for the role of known risk factors in the timing of decline and symptom onset in Alzheimer's disease (AD). This groundbreaking epidemiological study of AD in a single northern Utah county began with an incidence and prevalence study in 1994. All adults over 65 years old in Cache County – a total of 5092 persons - were identified and followed prospectively (since 1994) through what will be four separate points in time. How and why investigators at Duke University Medical Center, Johns Hopkins, Utah State University, and the University of Washington chose to focus on this relatively remote Western county illustrates one important way to answer questions about risk for AD.

Why study Cache County, Utah?

Older men and women in Cache County have life expectancies 10 years on average longer than the US population as a whole. This longer life expectancy facilitates studies to determine the prevalence of dementias across the ENTIRE life span. It also allows us to more fully explore the effects of potential factors, which may enhance risk of developing dementia or may delay or prevent its occurrence. Another advantage of the Cache County study rests on the nature of the population and the ease of locating and tracking people over time. The population is generally quite healthy, due in part to strong local prohibitions on alcohol use and smoking (90% are from the Church of Latter Day Saints, "Mormons"). They are well educated, have strong community ties, and have been historically very receptive and cooperative in studies.

This close-knit rural community is made up of large families with excellent genealogical records. This means that most research subjects will have a large number of family members who know them well. The relative isolation of this rural community limits the number of health care professionals and services from which to gather corroborating information. Most important, the Utah State University investigators are trusted members of the community who highly value the older members participating in the study. This trusting relationship and nurturing attitude has resulted in a 90% response rate from all older persons in the county – an unusually high rate by any epidemiological research standards.

What were the first findings from these studies?

Initially, the study explored the prevalence of AD in the population and then three years later examined incidence (new cases over time). In these two waves of study there was a particular emphasis on defining the role of known genetic risk factors (e.g. apolipoprotein E) and environmental risk factors (e.g. medication use) on the occurrence rates of AD across the lifespan. In this initial work, approximately 350 people were identified with dementia, 220 of whom had AD. In the later wave of study, done 3 years later, 186 new or "incident" cases of AD were found. The rates for dementia occurrence are fairly similar to other large population studies of dementia, suggesting that fewer than 10% of the population over age 65 suffers from these disorders.

What did we learn about prevalence and incidence of Alzheimer's disease?

The study first has been able to demonstrate that AD increases in both men and women over 80 years old. This was not too surprising as we know the disease is strongly age-associated. However what was novel, is that because of the population's long-lived nature, the occurrence rates in the very old could be better understood. Surprisingly, 30% of the very old seem to escape AD. The prevalence and incidence data suggest that women are at a somewhat higher risk of AD than men, especially women over 85 years old. The diagnosis of these people used the strictest standards including cognitive testing, physician examination, diagnostic consensus conferences and autopsy confirmation of over 100 persons to date. These findings are similar to recent findings suggesting about 60% of persons with dementia have AD or AD with vascular dementia.

What about APOE4 as a risk factor?

The study confirmed the findings from Duke and elsewhere that the APOE- e4 gene influences the risk of AD and the age of onset. Importantly, the findings indicate that APOE does not account for all of the risk and that a portion of individuals with an e4 gene can survive to late ages without dementia. This finding suggests that there are likely other genes that play a role in dementia risk, both some that enhance risk and others that protect or mitigate the effects of bad genes. It may also be that there are other non-genetic factors, such as environmental exposures, which may play a role and interact with an individual's genetic predisposition.

What about exposure to medicines and risk of AD?

The study has also demonstrated that some common medicines may have disease-modifying effects and that the timing of the use of these compounds may be critical in terms of their effectiveness. Some medicines may be effective only just before disease onset, and other medicines are only protective if taken years before symptoms develop or disease is diagnosed. What this means is that some preventive medicines may need to be taken for long periods before symptoms develop in the pre-clinical (prodromal) or mild cognitive impairment phase. Further, these potential preventive or protective medicines may be different from the current symptomatic treatments for persons with AD such as the cholinesterase inhibitors like Aricept, Exelon and Reminyl.

What about estrogen replacement therapy and risk of AD?

From the Cache County Memory study estrogen replacement therapy (ERT) seems to be one approach that is effective in delaying onset of AD but it may need to be used for long periods of time to exert its effects (e.g. 10 years or more). The use of these compounds for dementia prevention is not yet established and needs to be very cautiously considered given the known risks of ERT use. However, if the findings prove true -that hormones are playing a role in preventing or delaying disease occurrence- this presents an interesting opportunity for drug development in AD- finding therapies that are safe and act in ways similar to these hormones.

What about anti-inflammatory drugs (NSAIDS) and risk of AD?

The Cache County Memory study has also looked at this issue. A number of case control studies and case-cohort studies to date have suggested that anti-inflammatory compounds like ibuprofen or naproxyn are protective in AD. The Cache County memory study confirms this association and suggests a lesser degree of protection with aspirin.

What about antioxidants, like Vitamins E and C, and risk of AD?

The study is currently looking at the role of vitamin use and preliminary findings reported at the Summer International AD meetings in Stockholm are encouraging. These studies suggest that supplemental use of Vitamin E in particular, or Vitamin E along with Vitamin C, has a protective association against the development of AD. Continuing study is ongoing to look at whether the same effects are conferred from dietary consumption of these vitamins, as opposed to supplemental vitamin pills. The new studies in the Cache County population include a food frequency questionnaire to permit assessment of the protective effects of these vitamins in food.

What have we learned overall from the Cache County Study?

Alzheimer's disease is not inevitable with aging. A large proportion of people, perhaps as high as 30% or more over the age of 80 years old seem invulnerable to the disease. APOE is an important gene in AD risk, but it is not the whole story. There are a significant number of older individuals living into their 90s who do not have AD and yet have a copy of the APOE-e4 gene Other genes are likely playing a role as are other non-genetic factors. To this end, common medicines or even dietary habits may actually have a disease-modifying effect. The timing of these medicine exposures and, the timing of other factors still to be discovered, may be critical in determining efficacy. Some compounds may be protective if used for long periods of time before AD onset; others may act over shorter windows, or throughout all stages of the illness.

What can we expect to learn from the 2002 and 2004 Cache County studies?

The continuing study examines the timing of a number of medicine, dietary, and other exposures (when, what, and how much) on the development of AD. The study now turns its focus to the earlier, pre-clinical or prodromal phases of AD and other dementias The study will attempt to define the early stages of the illness at all ages, and will look at whether a variety of genetic and environmental factors affect the trajectory of cognitive decline and the rate of conversion from mild symptoms to AD. In-depth studies of cognitive change in the entire

population will provide more precise incidence estimates for people over 85 years old. These studies will answer questions about which clusters of cognitive test items are most predictive of pre-clinical Alzheimer's disease (those persons who will progress from mild cognitive impairment to AD) and when may be the most advantageous time to target certain therapies to prevent or delay onset of Alzheimer's disease. Stay tuned.

Editor's notes: Dr. Welsh-Bohmer will present updated study findings at Duke's Bryan ADRC 17th Annual Conference, February 13-14, 2003. Dr. Donald E. Schmechel, Bryan ADRC Director, appeared on Joe Graedon's NPR Radio Show, "The People's Pharmacy," on September 28, 2002. Check www.wunc.org/tpp for the online version.

THE SEVENTEENTH ANNUAL
JOSEPH AND KATHLEEN BRYAN

Alzheimer's Disease Research Center
CONFERENCE

ALZHEIMER'S 2003:
ADVANCES AND CHALLENGES

Thursday and Friday
February 13-14, 2003

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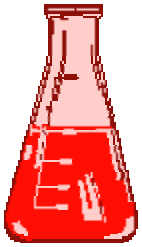


Memantine: An Update

By P. Murali Doraiswamy, MD
Duke Department of Psychiatry

Editor's Note: P. Murali Doraiswamy, MD is a physician and Alzheimer's disease researcher in the Department of Psychiatry at Duke University. He was the keynote speaker on Alzheimer's disease treatments at the 2001 Bryan Alzheimer's Center Conference at Duke. Dr. Doraiswamy receives research grants and provides consultation to many companies manufacturing and testing Alzheimer's medications, including companies testing Memantine.

What is memantine?

Memantine is a promising new drug for treating Alzheimer's disease and vascular dementia. It has been available in Germany since 1989 where it is now a standard prescription for dementia. In July 2002, memantine was approved by the European Union for treating moderately severe to severe Alzheimer's disease. Also, this year, memantine won its discoverer the "German Industry Innovations Prize" as the first treatment for advanced Alzheimer's disease. Memantine is marketed in more than 20 countries under the trade names Akatinol, Axura or Ebixa.

What is Memantine's Status in the US?

A New Drug Application (NDA), which is the formal request for approval, was submitted to the FDA on July 31st, 2002. It is being developed in the US initially for treating people with moderate to severe Alzheimer's disease. Until this approval is granted, memantine **remains an investigational drug.** However, based on memantine's track record in Europe **(although early European studies would not meet current US standards for clinical trials)** and the latest **unpublished** clinical trial results, there is optimism that the drug **may** become available in the US by 2004.

How Does it Differ From Current Treatments?

Current approved prescription treatments help the Alzheimer brain temporarily compensate for the loss of a brain signaling chemical called acetylcholine. These prescription medications are indicated for mild to moderate Alzheimer's disease. A second brain chemical, termed glutamate, also helps with normal learning and memory formation. However, abnormal glutamate spikes can damage or even kill nerve cells. Such spikes may underlie brain damage during strokes or dementia. Memantine **appears** to protect against these spikes while not interfering with normal memory formation. It's a little bit like the voltage stabilizer for computers or VCRs to protect against dangerous surges in electricity. In experimental (test tube) studies, memantine retards the production of abnormal Alzheimer plaques.

What does memantine do in Alzheimer's disease?

More than 90 clinical studies have been conducted with memantine worldwide in several thousand patients. **Findings from the latest US clinical trials have not been published.** In European studies, memantine has been found to benefit people with dementia, and specifically those with advanced Alzheimer's disease. A large study completed one year ago in the US

showed that memantine was better than a sugar pill on measures of cognitive abilities as well as activities of daily living in people with advanced Alzheimer's disease. Memantine was said to reduce the time commitment associated with caring for a patient by more than 50 hours each month and reduce caring costs by about $824 per month. The optimal dose for memantine for treating Alzheimer's disease in the US will be listed on the final product label **if and when it is approved for prescription use. Memantine is not a cure for Alzheimer's disease.** Families should have the same realistic expectations of memantine that they would have for any new treatment.

Can memantine be combined with current Alzheimer treatments?

Because memantine acts in a way that is different from Aricept, Exelon or Reminyl, it is hoped that individuals who take it simultaneously with the other drugs will gain greater benefits. An experimental animal study done in the US as well as clinical studies in Germany showed that memantine did not interfere with the effects of currently approved treatments and that the combination was tolerated well. Based on these preliminary findings, a large study was undertaken in the US to determine whether the addition of 20 mg daily of memantine in those already taking donepezil provided greater benefits than donepezil alone. This study involved 403 patients with moderate to severe Alzheimer's disease. At the end of 6 months of treatment, those taking both memantine and donepezil were found to have better cognitive outcomes than those taking donepezil and a sugar pill.

Does memantine work for vascular dementia?

Yes, memantine appears to help in vascular dementia as well. **However, as of this date, memantine is not approved specifically for vascular dementia or Alzheimer's disease.** In 2002 two large studies of memantine (321 patients in France and 579 in United Kingdom) found cognitive benefits for people with mild to moderate vascular dementia.

How safe is memantine?

Memantine appears to be fairly well tolerated. It appears to have a good safety profile. Nausea, dizziness, restlessness, tiredness and headache are some of the reported side effects. As with any drug, one should consult a doctor and the product label when and if the drug is available for the full updated listing of side effects and precautions.

How can I get memantine now?

Several mail order pharmacies claim to be able to obtain memantine for US patients if they have a prescription from a US doctor. **I cannot make any recommendations about obtaining memantine in this way.** Duke and several other sites in the US are currently conducting clinical trials with memantine and other drugs for Alzheimer's disease. For more information about Duke Psychiatry trials, call (919) 668-2572.

See also: Alzheimer's Association (2/2002) **Facts: About *Memantine*, An Investigational Alzheimer's Drug.**

DUKE INSTITUTE ON CARE AT THE END OF LIFE

Tulsky Honored For End-of-Life Research

James Tulsky, M.D., Associate Director of the Duke Institute on Care at the End-of-Life, was honored at the White House July 12 for his research into the quality of life at the end of life.

A general internist at the Durham Veterans Affairs (VA) Medical Center and an Associate Professor of Medicine at Duke University Medical Center, Tulsky was one of 60 researchers from across the nation—including three others from Duke—who were recognized for their 2001 Presidential Early Career Awards for Scientists and Engineers (PECASE), a special recognition for young federally-funded investigators.

The research, which was funded by two grants from the VA totaling $550,000, is designed to define the attributes of a "good" death—one that eases the transition for the patient—and to create a method to measure the quality of life for dying patients.

Tulsky and colleagues identified six possible interventions designed to improve quality of life at the end of life—pain and symptom management, clear decision-making, preparation for death, completion, contributing to others and affirmation of the whole person.

His research has shown there is no one definition of "a good death" and that wide disagreement exists about the importance of such issues as dying at home and the use of life-sustaining treatments.

Editor's notes: Duke's Bryan Alzheimer's Conference participants may remember Dr. Tulsky's popular workshop "Making the Tough Decisions: Talking with Patients and Families about End-of-Life Care" at the 2001 Alzheimer's Conference. Check out the new and very helpful Advance Care Planning Guide, Isn't ItTime We Talk? How to Plan for Your Care at the End of Life, from www.carolinasendoflifecare.org.

Wisdom

You can tell whether a man is clever
by his answers.
You can tell whether a man is wise
by his questions.

Naquib Mahfouz

The Latest Research on Healthy Aging

Ten Tips for Healthy Aging (2002)

No known substance can extend life, but your chances of staying healthy and living a long time can be improved. Check out ten tips from the National Institute on Aging for staying healthy as you age.

- Eat a balanced diet, including five helpings of fruits and vegetables a day.
- Exercise regularly. Check with a doctor before starting an exercise program.
- Get regular health check-ups.
- Don't smoke. It is never too late to quit.
- Practice safety habits at home to prevent falls and fractures **(See Page 11)**. Always wear your seatbelt in a car.
- Stay in contact with family and friends. Stay active through work, play and community.
- Avoid overexposure to the sun and the cold.
- If you drink alcohol, moderation is the key. When you drink, let someone else drive.
- Keep personal and financial records in order to simplify budgeting and investing. Plan long-term housing and money needs.
- Keep a positive attitude toward life. Do things that make you happy.

Editor's Note: The June, 2002 Scientific American quotes Jay Olshansky representing 51 aging researchers offering this important caveat to tips for healthy aging:

Anti-aging products are a multibillion dollar industry and a disturbing and potentially dangerous trend. These entrepreneurs are promoting anti-aging products that they claim will slow, stop or reverse the processes of aging. In most cases, there is little or no scientific basis for these claims. The public is wasting money on the products, some of which may be harmful. "There are no surgical procedures, vitamins, antioxidants, hormones or techniques of genetic engineering available today that have been demonstrated to influence the processes of aging."

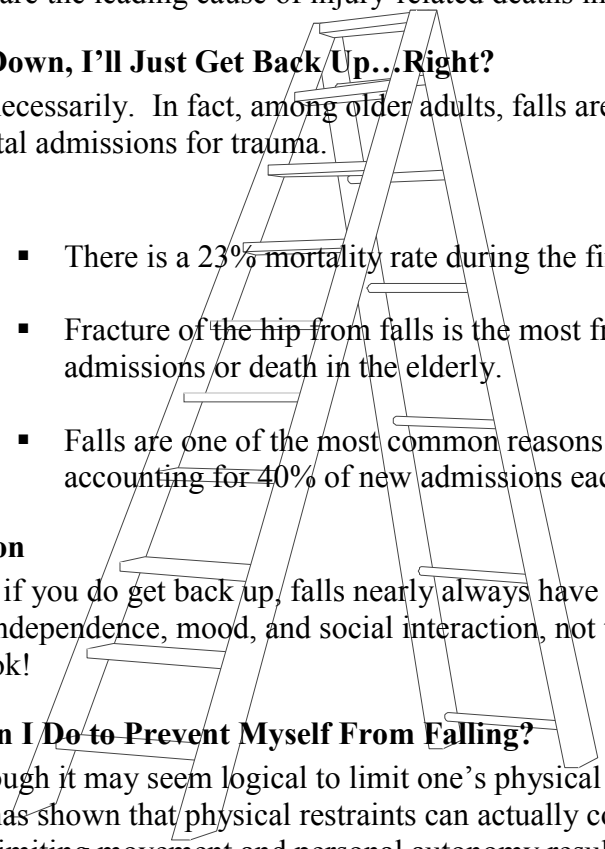
Falls

Who Cares About Falls?

Anyone can fall. Accidents happen. However, the fact that one in three adults over the age of 65 falls each year cannot be overlooked.

Did You Know?

Falls are the leading cause of injury-related deaths in persons over the age of 65.



If I Fall Down, I'll Just Get Back Up…Right?

Not necessarily. In fact, among older adults, falls are the most common cause of injuries and hospital admissions for trauma.

Beware

- There is a 23% mortality rate during the first year following a hip fracture.
- Fracture of the hip from falls is the most frequent single injury leading to hospital admissions or death in the elderly.
- Falls are one of the most common reasons for nursing home admissions, accounting for 40% of new admissions each year.

Conclusion

Even if you do get back up, falls nearly always have a negative effect on functional ability, sense of independence, mood, and social interaction, not to mention the tolls on your pocketbook!

What Can I Do to Prevent Myself From Falling?

Although it may seem logical to limit one's physical activity in order to prevent falls, research has shown that physical restraints can actually contribute to fall-related injuries and deaths. Limiting movement and personal autonomy results in muscle atrophy and functional decline.

Approach

- Maintain an exercise program that improves strength, balance, and coordination.
- Remove tripping hazards, use non-slip floor mats, and install grab bars next to the toilet and in the tub/shower. Get rid of clutter in your home.
- Ask your doctor to review medication in order to reduce their side-effects and interactions. The more medications you take, the greater the risk of falling.
- Use a nightlight or keep a flashlight by your bed.
- After awakening to go to the bathroom, sit on the side of your bed for a few minutes before standing up or keep a portable toilet close by to minimize falls at night.

- High risk fallers can wear protective hip pads to effectively prevent hip fractures (some people won't wear these!)
- Have an eye doctor check your vision each year. Take extra care when adjusting to a new eyeglass prescription, especially bifocals or graduated lenses.
- Take Vitamin D and calcium supplements.

Factors that Predict Falls

- A history of previous falls
- Delirium (confusion), especially in new onset falls
- Urinary incontinence
- Drop in systolic blood pressure following meals
- Drop in blood pressure when standing from a sitting position
- Muscle weakness
- Poor walking ability and one-leg balance
- Alcohol use
- Restraints
- Depression
- Poor vision
- Psychoactive drugs and polypharmacy, especially antidepressants and anti-anxiety medications
- Frequent need to urinate at night
- Environmental hazards, such as slippery floors, uneven floors, poor lighting, loose rugs, and unstable furniture
- Osteoporosis and poor bone mineral density
- Vitamin D deficiency

Measures of Risk

Time how long it takes to stand up from a sitting position. If it takes more than 4.5 seconds, you have an increased risk of falling.

Is it difficult to stand while holding a full glass of water? If so, you have an increased risk of falling.

In order to improve one's balance, perform this simple exercise for 2-5 minutes every day.

1. While standing, place your hands on a counter top or desk to balance yourself.
2. Lift one foot off the ground and balance yourself.
3. Now remove one hand and balance yourself, using your one planted foot and one hand.
4. Hold this position as long as you can WITHOUT FALLING. Repeat, using the opposite leg and hand for balance.

From *St. Louis University* "*Aging Successfully*" 2002 and Dr. Kathy Shipp, Duke Aging Center

Prescription Benefit Cards Offer Help to Medicare Families

Pfizer and Novartis have recently announced two programs designed to make prescriptions more affordable for low-income elderly who lack drug coverage. This news is of particular interest to Alzheimer families since both companies are manufacturers and/or distributors of drugs specifically designed for Alzheimer patients. The goal of both programs is to help the neediest of Medicare. Once accepted, consumers can use pharmacies of their own choice. With the Pfizer Share Card seniors pay $15 for a 30-day supply of Pfizer medicines, including Aricept, which is manufactured by Eisai, and drugs for diabetes, high blood pressure, high cholesterol and depression.

For more information on the Pfizer Share Card call

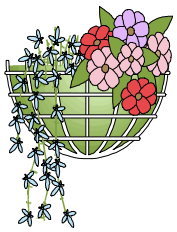
1-800-717-6005
www.pfizer.com

For more information on the Novartis Care Card call
1-800-974-CARE(2273)
www.pharma.us.novartis.com

The Novartis Care Card provides a 25% discount off the wholesale list price of drugs that Novartis manufactures, including Exelon, and drugs that treat high blood pressure, high cholesterol and osteoporosis.

North Carolina Senior Care Prescription Drug Assistance and Medication Management Program.

Eligible older adults may use this new discount card as of November 1, 2002. Applications—available from Senior Centers, Departments of Social Services or Public Health, hospitals, clinics and pharmacies. Eligible: 60+, low-income N.C. resident with no other insurance coverage for prescriptions. Coverage: 60% of the first $1000 costs of drugs for Chronic Obstructive Pulmonary Disease (COPD), cardiovascular disease or diabetes mellitus.



Grandmother

By Elizabeth Clark
Durham, NC

I walk through the electronically locked doors, holding my breath. I'm still not accustomed to the smell of diapers associated with my grandmother. I find her sitting on the couch, staring into the recesses of a fake Christmas tree. Her hair is short now. I hold her hands, which are slightly cool and fragile, like naked birds' wings. She receives my kiss with a soft, "Hello dahlin," though I doubt she knows who I am. We sit together on the sofa. She rubs my hands and tugs absently at my fingernails. I bend my head lower to try to catch a word or two of the low babble she speaks to no one in particular. I understand a few disjointed phrases, "Suitcase" "wouldn't it be…". This is one of her more talkative days. Sometimes she just sits, silent in her shifting world.

My grandmother has Alzheimer's Disease. It is a stealthy disease that cuts the memories that tie people together. It cripples proud women like my grandmother, who spent their whole lives perfecting every detail--her hair always neatly curled, serving sandwiches on china plates with pineapple and lettuce garnishes. She used to mop the kitchen after every meal. She rubbed fingerprints off counter tops, tucked hospital corners, decorated holiday tables. Everything in its place.

She and I used to play with the doll house my grandfather made for my mother when she was a child. We'd spend hours making up stories about the Johnsons, as we called our doll family. Then, after sunset, I would crawl in bed and she would read Swedish fairy tales of trolls and princes as I nodded off to sleep. When I got older, she would let me join her for a cup of midnight tea. I used to sit on the kitchen counter with my cup of tea, my bare feet dangling while she told me stories of my mother as a child. I talked to her about the future, about wanting to work for the Peace Corps, or be a senator. She'd smile and stroke my hair, "Dahlin, do whatever makes you happy."

It is so hard to believe this age-bent woman is my grandmother. She does not even look the same; her hair is cropped and straight, she wears slacks and tennis shoes. The difference makes it easy to see her as a little old lady, someone else's grandmother. Easy to smile and kiss her cheek. Then she speaks. That is when it hurts, because it really is her voice.

Some days, I leave the nursing home and roll the windows down on the highway, letting the air chill my anger and staunch my tears. I know she is dying. And in the face of her disease, her memories turned to misfired neurons, all I can do is what she did for me as a child: hold her hand.

Advice
©Henry Walker
July 2, 2001
Durham, NC

don't expect anything from Mother now
except what she freely gives,

as hard as it is
don't go for the recognition
of your face
a name
a memory,

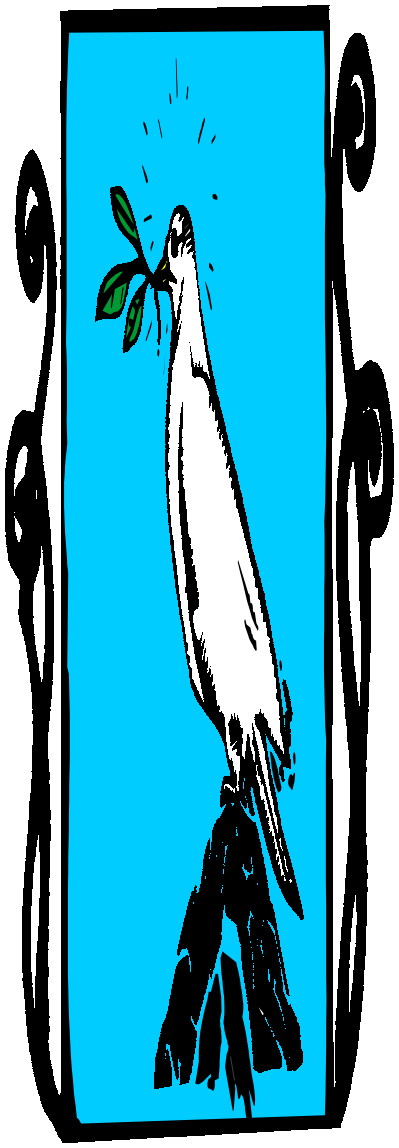
don't go for a conversation
you start,
because your words work for you
and not for her,
her words work for her
she knows what she's saying
and we should just go along for the ride,

don't correct her,
don't disagree with her
'cause if you do
you're piling one more brick
onto the heavy load of frustration
she's already carrying,

she's still giving
but we have to work hard
to appreciate what we're getting.

From: Walker, HH (2001) The Maze and Her Path: The Story of My Mother Within the Story Alzheimer's Tells. For info—Punmaster@aol.com.

Truth
The difference between truth and fiction: Fiction has to make sense.
Mark Twain



They Make Her World Safe

©Henry Walker
May 24, 2002

Mother feels as a little girl,
lost
somewhere where she can't find home
and home can't find her,
bewildered
because the input and output of words
don't anchor her,
don't reassure,
only the music of the lullaby can comfort
the smile on the face,
the love in the laugh,
the food and drink,
those who work with her
can be lost and bewildered too
when Mother cries for her mama
when she is scared,

what an amazing gift of art and love,
when caregivers build a safe world around her,
when she can trust them that it will be all right,
that she won't fall,
that she won't be left alone,
that all who need care are taken care of.

the caregivers' love and laughs for her soul
their love and actions for her body
just balance how lost and bewildered she always feels.

Not Fully Here
©Henry Walker
July 9, 2002

What does Mother give now?

No advice that we can fathom. . . .
No stories or opinions whose structure grows in the telling. . . .
No precise give-and-take where our words
narrow
and build on each other. . . .

We can't come in with an agenda for her to follow
so what can we do?

We can deny our pain, our frustration, our avoidance,
we can believe that she understands what
she is thinking & feeling & saying
despite how much it all sounds like nonsense,
we can feel for the old patterns,
the stock ways of phrasing we remember,
we can nod our head in agreement,
even when not sure what we are agreeing to,
we can pick up clues her eyes drop
and we can speak to those eyes
with a funny action, a comforting smile, a touch,
and we can reach her heart with a kiss,

Today that is what I do:
she works to read my t-shirt and gets the first two syllables right
and then guesses in some kind of free association
which makes no sense to her
and she comments on how crazy that all sounds,
she pauses, holds up both her hands, stares intensely,
and then counts off the fingers of each: 1…..2….3….4….5,
her eyes are drawn to the cartoon network
where the bold simplicity of sketched story catches her
and she tells me of problem and possibility within the scene,
like an impressionistic painting gone wild
there is a picture there when she talks
it is just way fuzzy,

It is hard to praise how full the glass is
when I see how much is no longer there,
I have to see with deeper senses
who whisper to me that the glass is still full
but like the grail the glass is no longer fully in our world.

Empathy

Emily Albera
Bath, NC 9/2002

What must it feel like to have someone thrust her hand into your hand,
her face into your face,
announcing and asking, "I am your daughter—remember?!"

The stranger seems to think you're supposed to remember,
remember everything that was and is.

You should remember the touch of her father,
the birth of your children,
the feeling of grandchildren warm in your lap,

How could you forget the weddings and funerals,
the farmhouse, the family,
a lifetime of loved ones who asked your advice?

You wish you remembered the places you went to,
the deeds you've accomplished
the person you sense that you used to be.

And still the lady persists--louder this time:
"Don't you remember?"
"Don't you remember me?!"

You don't remember.
And you feel the expectation, the pressure
of someone else's need for you to remember.
But you don't.

So you grope for recognition that never comes.
You wish you could help the nice face
that fades into silence and disappointment.

You wish you could fix it—the face, the disappointment, your memory.
But you can't.

And we both feel the pressure.

Duke Family Support News

Caregiver Internet Radio Program will feature Lisa Gwyther

Listen to Lisa Gwyther, Education Director, Bryan ADRC, live on Saturday, October 19, 2002. Lisa will be a guest on Jacqueline Marcell's internet radio program, "Coping with Caregiving," and will be discussing Alzheimer's family support. The show will take place at 6:40 pm ET, but it will be archived and available for listening online anytime within a few days after the live show.

Http://12.162.161.64/cart/ProductDetail.asp?PR_ProductID=317.

Congratulations to Alzheimer's Association Advocates

North Carolina Alzheimer's Association Chapter advocates led a successful Summer 2002 campaign to restore projected cuts in state Alzheimer's funding for chapters and Duke's Family Support Program. We are grateful to members of the North Carolina Legislative Conference Committee for listening to the voices of Alzheimer's families.

New Toolkit for Helpline Staff

Lisa Gwyther and Edna Ballard developed a 2002 NC Information and Assistance Toolkit: Working With Families of People with Memory Disorders. 500 copies were distributed free to NC county aging information specialists, NC Alzheimer's Association Helpline volunteers, and NC Alzheimer's Demonstration grantees. The positive response to the Toolkit has been overwhelming. The toolkit is on the NC Division of Aging website (www.dhhs.state.nc.us./aging/home.htm), and an at-cost reprinting of the Toolkit is planned.

"And Thou Shalt Honor…"

This is the title for an October 9, 2002, 9-11 p.m. (EDT) PBS-TV Special on Family Caregiving. NC Public Television will **re-broadcast** this important family show during Thanksgiving week in November, 2002. The **re-broadcast** will be from 7-9 p.m. with an immediate N.C. follow-up show **Caring Voices** which will feature NC family caregivers, Lisa Gwyther, and other caregiver support program leaders.

Smiles
Everyone smiles in the same language.
Unknown

Have You Heard About?

AARP. Caring for Those You Care About: Home and Community-Based Services – Supplement to Reader's Digest 9/2002, www.aarp.org/life. Knowing Public Benefit Programs, Dealing with Long-Distance Issues, Providing Care at Home (2002 Information Sheets).

And Thou Shalt Honor: The Caregivers Companion (2002). Book based on PBS-TV special airing October 9, 9 p.m. $24.95 single copies available from Barnes & Noble.

Beginning to Make Sense: A Guidebook for Persons in the Early Stages of Alzheimer's Disease and Their Caregivers. (2000) Publishers: Adult Day Services of Orange County (ADSOC). Available to families at no cost, by calling ADSOC at (714) 593-9630. Providers may obtain copies for a suggested donation of $10/each.

Bell, V and Troxel, D. (2002). A Dignified Life: The Best Friends Approach to Alzheimer's Care. Health Communications, Inc. Paperback at $12.95 in bookstores. For family care at home—excellent sections on activities and spirituality.

Birren, J and Cochran, K.N. (2001). Telling the Stories of Life Through Guided Autobiography Groups. Baltimore: Johns Hopkins, University Press. www.press.jhu.edu

Harris, P.B. (Ed). (2002). The Person with Alzheimer's Disease: Pathways to Understanding the Experience. Baltimore: Johns Hopkins University Press, paperback. www.press.jhu.edu.

Kidd-Madison, N. (2000). Living with John: Caring for a Loved one with Alzheimer's Disease. Self-Help Books.com. Greta, LA. Farmer's wife's account with practical tips in large print paperback.

Kirkman, D. (Summer, 2002). Lawyers and Elderly Victims of Telephone Fraud. NC State Bar Journal: 24-28. Important Information for Alzheimer's families.

Marosy, J.P. (2002) Elder Care: A Six Step Guide to Balancing Work and Family. $14.95. Electronic versions at www.bringingeldercarehome.com or call (508) 854-0413. To order by mail: Bringing Elder Care Home Publishing, 52 Holden Street, Ste 100, Worcester, MA 01605.

NC Family Caregiver Support Program. (October 2002). Family Caregiving in NC—An Information Sheet for Family Caregivers. Invaluable information available from NC AARP and the NC Division of Aging.

Pillemer K, Hoffman R and Schumacher M. (2000) The Nursing Assistant's Survival Guide. $11.95. 800-348-0605 or www.frontlinepub.com.

Rantz, M., Popejoy L., Zwygart-Stauffacher M. (2001). The New Nursing Homes: A 20-Minute Way to Find Great Long-Term Care. Fairview Press: Minneapolis, MN. Fax number (314) 771-8575.

Summers, S and Krohm, C. (2002). Advance Health Care Directives: A Handbook for Professionals. The American Bar Association.

Websites

www.fullcirclecare.org. Excellent new site supplies support information and assistance needed for N.C. caregivers.
www.togetherrx.com. New prescription drug benefit card for Medicare eligible without any public or private prescription drug benefits. Endorsed by the National Council on Aging.
www.niehs.nih.gov/external/faq/alum.htm. 2002 facts on aluminum and Alzheimer's Disease.
www.alz.org/internationalconference/newsroom.htm. Press releases from July 2002 Stockholm International Alzheimer's research conference.
www.abpi.org.uk. Click "Publications, Patient and Their Carers, Target—Alzheimer's. British Alzheimer's Society and Pharmaceutical Company's patient/family consumer booklet on medications with excellent illustrations. 2002.
www.pfizer.com/brain. Brain development and results of brain malfunction.
www.alzforum.org. Latest research, conferences and links to 34 journals and scientific newsletters.
www.mc.uky.edu/nunnet. Research study follows 670 nuns and offers insight on aging and Alzheimer's disease.
www.spry.org/sprys_work/education/evaluating_health_content.html. Evaluating Health Information on the World Wide Web, a hands-on guide for older adults and caregivers.
www.aarp.org/grandparents. See "for grandparents raising grandchildren"or sharing family history, long distance grandparenting, making wise toy and gift choices.
www.aarp.org/ageline. Search health/healthcare for Alzheimer's or caregivers.
www.brainexplorer.org. Images that show how disorders such as Parkinson's disease, Alzheimer's disease, depression, anxiety, migraines and stroke affect the brain.
www.cdc.gov/ncipc/pub-res/toolkit/toolkit.htm. Toolkit to prevent falls in older persons.
www.journalkeepers.com/goodgrief.htm. Book designed to teach children the basic concepts of death and to help them grieve and grow in healthy ways. $14.95.
www.soundcovenant.org. Music and workbook designed to equip caregivers with visitation skills to use music that relieves pain and anxiety, while visiting the sick and those near life's end.
www.nclifelinks.org. New N.C. online Advance Directive Registry. Click on the heart-shaped icon or call 919-807-2162. A simple file number and passcode allow family members and physicians access to your 1) living will, 2) health care power of attorney, 3) advance instruction for mental health treatment and 4) organ donation declaration.
www.cancercare.org. Helping Hand Guide and Talk to a Social Worker sections are quite helpful for people with cancer and their families. Toll-free (800) 813-4673 for social work counselors.
www.elderlawanswers.com. Primers on Medicaid, Medicare, estate planning, long-term care insurance and nursing home decisions. Database of "screened" elder law attorneys.
www.americangeriatrics.org. "Geriatrics at your Fingertips"—a guide to assessment instruments, diagnostic testing and management strategies.
http://dietary-supplements.info.nih.gov. Reliable evidence about dietary supplements.
http://altmed.od.nih.gov. National Center on Complementary and Alternative Medicine.
www.hdis.com. Incontinence supplies.
www.partnersagainstpain.com. Pain management information for professionals and consumers.
www.positiveendings.com. One of the first internet-based obituary writing services. Goal: to help families create a keepsake obituary.
www.asaging.org/cdc. Cognitive Vitality Awareness Program is the second module in the CDC health-promotion and disease-prevention program.